Moving Beyond Hope

Consumers & Communities in Policy Development

Perspectives from four Atlantic region projects

Health reform across Canada has reflected government concern about the gap between high health costs and positive health outcomes, and the growing Canadian debt. In the last few years health reform has been in motion in Atlantic Canada, with three Atlantic Provinces - Newfoundland, Nova Scotia and Prince Edward Island - adopting regional health boards. Although New Brunswick reform did not involve full regionalization, hopes and concerns about health reform of community and consumer groups in each province were similar:

- Hopes for the broad goals of health reform: promoting wellness rather than focusing on illness; involving communities, families and individuals in planning and delivery of integrated services, and emphasizing community-based services
- Concerns for: cuts to existing health programs; vulnerability of people most marginalized or stigmatized; strain on families, especially women, providing additional care and support for health problems; lack of consumer/ community involvement prior to health reform.

Since 1995, the Health Promotion and Programs Branch of Health Canada has supported projects in each Atlantic province. The projects focused on consumers or communities in policy development. Each used a community/consumer development approach. Each was set in the context of previous and subsequent work in the health area, and within provincial health reform.

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This paper was written by Julie Devon Dodd, Moyra Buchan, Monica Chaperlin, Doug Crossman, and Jane Oram, who met in Halifax to share experiences from our work related to health reform and to prepare a workshop for the Canadian Public Health Association Conference in July 1997. The dialogue and analysis of our collective work are presented in this paper. The paper was finalized following the workshop.

Context of Policy Development

Federal and provincial governments invited citizens to participate in the health reform process through many avenues. Opportunities included the National Forum on Health local consultations, appointment to provincial or regional policy or planning groups, telephone and community consultation surveys on health needs, consultations on policy through broad health goals.

The hope generated by health reform was found in the desire that true reform - not just a shift in ideas and values (restructuring), but also a shift in power to define problems and solutions - was possible.

Governments and communities are promoted as partners in health reform with shared concerns: to more clearly define what determines health and how to promote it, and how to more effectively integrate programs and services. Another, less visible, partner in health reform and policy development is the private sector. The health care industry is advocating for increased privatization of health care.

Governments communicate with communities and the private sector; the private sector communicates with government and; communities communicate with government. Few forums exist which bring all sectors together around the issue of health reform.

The community movement through women's, mental health and other advocacy groups brings issues to government through community development processes, and governments urge public participation in health care policy. What are the conditions under which this can be a successful partnership?

Common Language

Information and communication are essential to citizen's involvement in health policy development. People need information about the policy development process, the partners involved and their spheres of influence. Partnerships need a common language that requires discussion of values through which terminology is interpreted.

Health reform confused citizens, in part, because of language. In some cases professional language was unclear (e.g. determinants of health), and in other cases the language of community was co-opted by government and used without acknowledging the process (e.g. empowerment). For health reform to succeed and for consumer and community participation to be more than token, capacity building of individuals, consumers, and communities is essential.

Consumers and communities participating in policy development requires a common language:

For example,

Capacity Building - preparing consumers and communities to use their full capacities to meet their needs.

Consumer/Community Participation - involvement of people in the decisions that affect their lives.

Healthy Public Policy - strategies and guidelines agreed to by governments, about keeping the environment, community and people healthy.

Health reform - not only a shift in ideas and values (restructuring), but also a shift in power to define problems and solutions.

Policy - commitment to a course or plan of action agreed to by a group of people with the power to carry it out.

Forces Affecting Participation

At any time, in any event, there are forces at play. Forces include not only the social, political, historical and economic context, but also people's perceptions and responses. Some forces at play for consumers and communities in policy development are clearly supportive, others clearly working against, and others still unpredictable.

Forces Supporting Participation

- **The fiscal agenda has a positive side**. The need to reduce health care budgets can lead to creative approaches. Also the reality or perception of chaos in the broader society creates both a need and opportunities to take control locally.

- **People have a desire to find solutions that work.** The fear that "no one will look after me" can motivate people to reassess values and rethink approaches. Values of sharing and caring lead to questions: What is our society about? What do we want it to be? Personal experience is understood as a force for change and grass roots work is legitimized Local, grass- roots expertise is reclaimed such as self-help and other community-based services (e.g. abused women). Consumers and communities demand demystification from professionals, "you have to explain this to me"; there is an increase in plain-language materials. People look to models of transformation.

- **Everyone wants to be seen as a good person and part of the solution**. The commitment of system and community people is affirmed, with understanding that there are allies who work in the system. Roles and relationships are becoming more equalized and professional roles redefined. There is a will to collaborate and move beyond adversarial positions. Principles and goals of consumer and community participation are developing within the system.

Forces Working Against Participation

- **The fiscal agenda has a negative side.** Cuts to existing programs and lack of funds for new approaches cause loss of faith in systems and feelings of insecurity. The fear "no one will look after me" can cause isolation and competition for "scarce" resources which increases poverty, polarization, alienation, and distress Staff working in systems are increasingly stressed. People's acceptance of a deficit agenda means loss of hope and apathy.

- **There is rapid change in principles and governments.** The speed of change means people are busier and more difficult to involve. The amount of information needed to make informed decisions can be overwhelming. A sense of chaos in the broader society leaves people feeling hopeless and cynical about politics. A lack of government policy on consumer participation means human and financial resources to value and promote community and social development is lacking.

- **The current system isn't working.** The contradiction between an economy based on consumption and the promotion of scarcity agenda are confusing. Global economy and corporations influence national economy and can decrease effectiveness of governments to act on decisions. A lack of system values and tolerance for equality in partnerships, including acknowledgment of power imbalances, can immobilize partnerships. The lack of public research that demonstrates success of other models (e.g. Wellness Models) means either the status quo or changes influenced by private sectors. There is a sense of leadership vacuum and tired leadership.

By understanding the various forces at play, strategies can be developed that decrease forces working against, and increase forces working in support of consumers and communities in policy development.

Stories from Four Atlantic Region Projects

Stories from each of the four Atlantic provinces tell in the words of project staff the successes and struggles of consumers and communities in policy development.

Speaking for Ourselves - Newfoundland

Why We Did It

Speaking for Ourselves Project (SFO) was a project of the Canadian Mental Health Association, Newfoundland & Labrador Division. It took place in 1995-96, in the context of the reorganization of the provincial health system into five health regions. The goal was to strengthen the capacity of consumers to become active participants in their new regional systems.

The project involved two groups: CHANNAL (Consumers Health Awareness Network Newfoundland and Labrador), a provincial network of mental health self-help groups which had been established for five years; and the Community Action Program for Children (CAPC), regional coalitions of Family Resource Centres which were in the beginning stages of organization.

CHANNAL had been consumer-driven from the start and had built a strong advocacy presence at the provincial level; local groups however were focused on self-help and the need now was to develop advocacy at the regional level. The CAPC groups, on the other hand, were initiated by professionals, but had the goal of 50% parent participation on their coalition boards within their first year.

It was expected that the CHANNAL groups, having a five-year history with leaders who were vigorous advocates, would be ready to make the move into advocacy, and the objective was for each group to start a communication and education process with their regional health boards. For the newly formed CAPC groups, it was anticipated that more specific preparation would be needed for parents to become active on their coalition boards. We wanted to find out whether learning from CHANNAL's history could assist the CAPC groups, i.e. did each group have to reinvent the wheel? We planned to include learning from CHANNAL's history in a skill development program for the CAPC parents.

What We Did

- Focus groups were held with CHANNAL members to gather information about key factors in the growth of their provincial advocacy movement.
- One-day needs assessment workshops were conducted with each participating group (in five regions for CHANNAL, and two regions for CAPC).
- Follow-up with the CHANNAL groups included a series of teleconferences and the development of materials for the groups to share with their boards.
- In response to the needs identified by the CAPC groups, a skill building program was developed, and this was delivered to the participating parent groups over a period of three months.

What Happened

CHANNAL: What emerged from the CHANNAL process was that groups that are focused on self-help will not necessarily move on to advocacy, and that readiness for advocacy is not a function of the length of time the group has been established. For the CHANNAL groups, there were many more important factors: individual composition, leadership style, organizational cycles, and particularly health. For some groups, self-help was all they wanted to do. There was, however, keen interest in advocacy in two more recently formed CHANNAL groups with substantial membership from survivors of sexual abuse. In these groups there was a strong current of anger and determination to change the system they had found unresponsive to their needs. Members of both groups went on to serve as consumer representatives on mental

health planning committees. Others chose to submit information about CHANNAL and the role of self-help.

All of the CHANNAL groups found the needs assessment workshops valuable opportunities to look at where they were and where they wanted to go. All welcomed the new information and perspectives that came out of them, and will use these in their own way and in their own time. But the move to advocacy within the timespan of the project was our agenda, not necessarily theirs.

CAPC: The needs assessments with the CAPC groups bore out the expectation that the parents wanted to build skills and confidence in order to participate in their organization. The skill development program focused on demystifying boards and committees, providing basic information about how organizations work, particularly the things it is often assumed people know or will just pick up. The parents practised running meetings, setting agendas, giving reports, brainstorming and solving problems, then went on to try out these skills in the real setting.

Having the group to support them as they became more active on their boards was crucial. They could discuss board meetings, understand what was going on, decide what they needed to say, make mistakes and learn from their mistakes. The focus was on skill-building, but people's self-confidence increased greatly as they developed new skills and started to experience the satisfaction of real participation.

By the end of the project, the objectives for parent representation on their boards were fully met. However, one group found participation easier because of the receptivity of the professionals involved. For the other group, on-going difficulties arose from the lack of conviction on the part of other stakeholders about the value of consumer participation. One of the interesting results of the skill development program was that it created an on-going mutual support group for parent participants in both CAPC sites.

What We Learned

Community development is about working with people where they are. One cannot impose an agenda for advocacy development, nor will learning about how advocacy emerged in on group necessarily apply to another. However, although in one component of the project we found that self-help did not necessarily lead to advocacy, in the other, the process of learning to be self-advocates did create a self-help dynamic.

We did clearly identify some of the learning needs shared by all groups in the project, however diverse: essentially the need to decode how boards work, to communicate basic information in plain language, to state unstated assumptions, to clarify expectations. The *Community Participation Resource Kit* produced by the project focused on doing just this, explaining what is often unsaid or assumed about boards and committees.

Readiness is crucial, not just on the part of consumer participants, but also on the part of the system. Federal policy committed the CAPC boards to parent participation, but the burden of learning and adjustment is placed on the consumers and a parallel process needs to take place with system people. Genuine belief in the value of consumer participation is essential to making it work. Although much lip-service is paid to the principle, all too often the inner conviction that "the professional knows best" prevails.

Women Influencing Healthy Public Policy - Prince Edward Island

Why we did it

Women's Network PEI sponsored this project focusing the concerns of members about health reform and women. The local media released information from government calling for suggestions of names for appointments to Regional Health Boards. The women raised many

questions - What is health reform? What authority do regional boards have? Who will be appointed? Will there be provincial standards? Research into these questions led to both hope and concern. The major concern was the lack of women's voices from the community, and the fear that reform would go ahead without hearing from women, especially the most vulnerable because of poverty, violence or other issues.

What we did

The project focused on community development work to help women develop skills to become active participants in decisions that affect individual, family and community health.

The project had three components -

- Advisory Committee with broad geographic and interest representation who developed and took ownership of the project
- Beyond Prescriptions - two 3-hour workshops to encourage women to define and take charge of their own health
- Women Taking Leadership - 6-hour workshop to inspire women to participate in community health reform meetings and join committees and boards.

What happened

The most predominant feeling about health reform by Advisory Committee members at the beginning of the project was worry, followed by excitement, curiosity, and confusion. Twenty-seven women, with diverse backgrounds, met for four day-long meetings over the year. At the end of the project every woman had advocated for herself and family, or community.

Nine *Beyond Prescriptions . . . Meeting Your Health Needs* Workshops were conducted in geographic communities, and six with special interest groups - youth, seniors, mentally handicapped, single mothers on social assistance. The purpose of the workshop was reflection and self-advocacy. Many women felt affirmed for their current coping and saw options for moving beyond coping.

Three *Women Taking Leadership - Inspiring Healthy Public Policy* Workshops were conducted in three different communities. The purpose of the workshop was learning about health reform and community advocacy. Many women were encouraged by the areas in which they felt power to advocate for change.

Women Influencing Healthy Public Policy:

- introduced holistic health and determinants of health concepts to broader community
- advocated for plain language and social change as part of health reform process
- established links between Women's Network and Health and Community Services system
- set up Women's Wellness Action Groups in two communities
- provided workshops province wide with many significant interest groups.

Some of the factors contributing to the success of the project were:

- participation of women province-wide from diverse backgrounds
- comprehensive, holistic approach that was inclusive
- partnering with local organizations to sponsor workshops
- paying for child care and transportation for women with limited resources
- supporting women who work in the Health and Community Services System.

Some of the barriers to success were:

- the comprehensive, province-wide approach with limited financial and time resources ($50,000/1 year)
- amount of time it took to understand the complexities of health reform.

What We Learned

- To prepare for consumer/community participation in policy development, many people need to focus on individual change

and self-advocacy before moving to social change and community advocacy.

- Clear communication is important about specific assumptions/beliefs about health care and about women, as well as roles, expectations, and clear language.
- Key links with the system are critical to make sure the system is ready for consumer/ community participation.

Healthy People - Healthy Communities - Healthy Public Policy
New Brunswick

Four communities in New Brunswick have broadened their definition of health and are now working to remove barriers to their citizens' well-being.

Why We Did It

The World Health Organization tells us that health is dependent on a full range of quality of life assets including peace, shelter, education, food, income, stable eco-system, sustainable resources, social justice and equity. What this broad definition of health suggests is that for a community to be healthy, all citizens must work towards accepting these prerequisites to health and incorporating them into all decision-making processes and policy structures. This shift in thinking challenges our communities to move from an old paradigm of health to one of promoting health. "Healthy Communities", an international movement, has been adopted by thousands of cities, towns and villages as a means to help communities make this shift. A healthy community is a place where all aspects of health are considered - education, housing, health, transportation, the economy, the environment and the family - and people realize how interrelated and inseparable these parts all are. It is characterized by unity, pride and confidence which arise out of the collective ability of leaders and citizens to come together. The shift in emphasis comes through a process whereby the citizens in the community are empowered to determine and address the health needs of their community.

What We Did

In 1996, a $60,000 grant from Health Canada enabled the New Brunswick Healthy Communities Group to engage four communities - Bathurst, Saint John, Stanley and the tri-community of Moncton /Riverview/Dieppe - in undertaking a healthy communities approach to community health needs definition and problem-solving. Although each community chose their own priorities and actions, all began by forming a steering committee, consisting of a diverse group of community members, to manage their healthy community project. They also engaged a staff person to support the work of the Steering Committee. As well, all used the healthy community tools: collaborative problem-solving, multi-sectoral involvement, citizen participation, an emphasis on community assets and capabilities.

What Happened

Highlights of two New Brunswick Healthy Community stories:

Stanley

Stanley is a rural community of 2400 people. Its healthy community project was facilitated by the Health Services Centre which established the Greater Stanley Community Awareness Committee - an intersectoral body involving students, seniors, health professionals, the village of Stanley and a number of community groups. This committee quickly determined the focus of their project - youth. They felt the foundation on which to build a healthier future for the village resided in fostering a more caring and supportive community for youth. In return, they felt their youth would help to improve the quality of life for the broader community.

The results of their first year of work are astounding! As part of an economic strategy for the community, the youth helped to prepare a community portrait of the demographic, economic, social, physical and cultural conditions of Greater Stanley; youth have assumed

leadership responsibilities for group needs - they've established a dance committee, sport committee, movie committee, ski club, Internet committee and peer helpers group; the Stanley winter carnival was re-established by the youth; a Wellness Forum was held which determined youth priorities and community action plans are now underway.

More businesses are supporting youth through Junior Achievement program and more employment opportunities. For example, in 1996 twenty-two students accessed summer employment compared to 3 youth in 1995. The Home and School and other community groups have invited youth to participate on their committees, an intramural program for elementary students has been established; summer recreational programs have been introduced and led by youth; a beach volleyball court was constructed; student training programs have been introduced and are increasing youth leadership capabilities for many community needs. The initial work has had a snowball effect in the community. Youth are now recognized as "contributors" to the community, are expressing themselves with more confidence and are providing leadership in the community. The success is due to the community as a whole working together to create organizations, places, programs and services that are responsive to the needs of their youth.

Saint John

Saint John - *healthy, proud, active, caring, enterprising, culturally vibrant and environmentally responsible.*

This description of Saint John citizens comes from the collaborative visioning efforts of hundreds of people who participated in a series of "healthy community" discussions. Saint John's healthy community project was initiated by the Community Health Centre which established the Greater Saint John Healthy Community Working Group involving local activists from business, government and community sectors. The Working Group chose to begin its project by involving the city's diverse communities in:

- describing what makes Saint John a healthy community
- determining a common vision
- establishing priority areas for community action.

The Working Group documented the results of the community dialogue in two publications - Healthy Community Discussion Guide and Healthy Community - Foundations for Action. Significant community initiatives are now being strengthened and incubated around 5 priority areas for action - pollution, unemployment, poverty, youth, and public safety. Saint John's healthy community story is destined to take root and multiply as increasing numbers of citizens: a) become involved in community learning and action, b) participate in multi-sectoral action groups, c) develop confidence in their combined knowledge and abilities, and d) generate success.

Bathurst and the tri-community of Moncton/ Riverview/Dieppe have equally good "healthy community" stories to tell. As these communities now celebrate and continue to develop their health, more communities in New Brunswick have begun a similar journey.

What We Learned

"Healthy Communities" is a positive and motivating process which enables any group or community to:

- develop a vision, or a roadmap, that articulates the priorities and 'common ground' shared by the group
- discover new abilities and strengthened relationships among community members and the collaborative means to address priorities
- undertake targeted actions to achieve desired 'health' improvements.

A "Healthy Community" initiative is more likely to be successful if the following principles are followed:

- start where the community is at
- focus on the community's assets and capacities, not their liabilities
- define a shared vision or mission
- work towards inclusive membership of all sectors and all levels of the community
- create a competent organization that has effective leadership, democratic decision-making, skilled staff, a planning system, effective communication and an effective use of available resources
- create a commitment to action and advocacy, not just to planning and developing reports
- bring hope and celebration to the process in the community
- understand that these efforts will take time and persistence.

CLEAR Consumer-Led Education and Action for Reform Nova Scotia

Why We Did It

The Canadian Mental Health Association - N.S. Division sponsored this project designed to increase the involvement of mental health consumers in health system reform. A number of previous consumer focused studies had identified a lack of opportunity, knowledge, skill development, and resource support as the key barriers to consumer participation. Consumers in N.S. have consistently argued that in order to correct the stigma and misconceptions about consumer's limited capacity to control their own lives, mental health policy had to insure that they had a voice in shaping the kinds of programs needed to enhance their health.

What We Did

The CLEAR project focused on learning what kept consumers well as opposed to what kind of services they needed. The project had three phases:

I Training consumers to conduct a series of focus groups in two health regions to identify what determinants affected consumer's health and what level of knowledge and participation consumers had in the health reform process.

II Prepare a report of the focus group results and begin a process of educating consumers, family members, community agencies, and mental health decision-makers about these findings. The Canadian Mental Health Association Community Resource Base Model was used to structure these meetings.

III Prepare a manual and train selected consumers to participate in their own health promotion as well as for better understanding formal policy/program development procedures.

What Happened

Phase I - A team of 8 consumers were trained to conduct 14 consumer focus groups in two health regions. These regions were chosen to compare rural/urban populations as well as to compare consumer responses from two areas showing a wide variance in per-capita program spending. The groups involved 135 consumers and were organized by community groups and providers. This phase of the project generally demonstrated a limited level of organization in the consumer movement in Nova Scotia.

Phase II - A series of community forums were conducted to engage consumers, family members, community groups and providers in discussing the finding of Phase I. The participants widely supported consumer opinion on health and health reform. Many participants felt the Community Resource Base an effective model for social action and that collective advocacy was a powerful force for change.

Phase II also included presentations to key decision-makers in the two health regions. The principle of involving consumers in policy development was endorsed, but constructive action to ensure the implementation of this principle has been limited.

Phase III - A training manual entitled, *Mental Health Consumer Participation in Self-Care, Recovery*

and Social Action was developed. Twelve consumers have been trained using a peer education model. A facilitator from the American based, National Empower Center, conducted the training. This training opportunity will be offered to consumers throughout Nova Scotia by the Canadian Mental Health Association.

What We Learned

- The focus groups generated information in an inexpensive manner.
- The consumer-led approach enhanced the trust level of consumers participating in the focus groups.
- The focus on health and health reform generated learning which would not have been gained if the focus groups had taken a traditional "service need" approach.
- The importance of health determinants (i.e. poverty, social support, education) as critical factors for effecting consumer's health were confirmed.
- The partnerships with other community and provider groups made important contributions to the project.
- The learnings about health reform reflect a similar level of confusion, frustration and anger found in the general population.
- The health concerns of consumers are no different than those of the general population.
- The stigma associated with mental health issues remains a key barrier to consumer participation.
- The involvement of consumers in health reform requires a policy which ensures knowledge, skill and resource development support.
- The health policy reform process starts with individual changes in thinking and behaviour.

Common Learnings

To succeed, problem resolution must involve those most affected. Cooperation to resolve problems is most likely when the different groups involved in an issue can identify their needs and collectively define the problem. Thus the needs of different players are considered in solutions.

The Canadian Public Health Association's Health Promotion Framework (building on the Ottawa Charter) describes five strategies for change and analyses the connections between them - reforming health systems, enhancing knowledge and skills, strengthening communities, building alliances, and advocating healthy public policy.

Projects in Atlantic Canada helped communities develop a common vision for health and alliances between communities and systems. The projects also developed tools to help build community capacity to participate in the health reform process. More importantly, all projects were successful in raising hope. Hope is the faith that sustains consumer and community participation.

However, hope itself is not enough. Moving beyond hope is demonstrated by concrete actions, strategies and policies. Projects had varying degrees of success in actually changing health systems. There was some progress - attention to plain language, individuals joining boards or committees, groups advocating at public meetings - but often the systems were not ready to work with the communities.

Consider Values

Values guide action. In organized systems, values are the core from which mission, goals, policies and programs develop. (See Organizational Environment Model - Figure 1) Involving consumers and communities in policy development should ideally be guided by values and supported by policies.

Consumer and community representatives feel disregarded by statements of experts such as "I don't care about consumer satisfaction. What I care about are good outcomes for my patients."

What are the values of the system in relation to consumers and communities? Do these values translate into policies about consumer/ community participation? What is the dynamic between the values of 'quality of life' and 'quality of outcomes'?

Be Realistic

Invitations by government to participate in policy development are often met with cynicism. Too often people have felt disrespected in the process, and excluded in the product. The response of participants is often - *the system doesn't really care about what we think, they just want to look good.*

Community participation in policy is most successful when people can relate it directly to their lives. Participating in municipal or hospital policy may be an appropriate scale for community people who are new to policy development. Another option is to help communities make the connection between national policy, for example, and experiences in their own back yard. Help people to think globally and act locally.

Set a realistic agenda for consumers' and communities' involvement. What are the boundaries of time, resources, legislation, programs that limit participation or outcomes? (It is difficult to change an entire system. It is more effective to focus on specific policies or program changes.) How can the links between today's needs and tomorrow's policy be made? What are the benefits to consumers and communities? Is there a gulf between the expectations of participation and the resources available?

Get Ready for Participation

Processes which introduce holistic health and determinants of health concepts to communities are an essential base for this work.

Participation by consumers and communities in policy development with government systems requires a degree of trust on both sides. Attention to building trust is the core of collaborative relationships.

Token "star" participants get identified from constituent communities to be the "representative". These representatives get invited to everything and eventually burn-out. The response of the system is sometimes - *consumers/communities aren't ready.*

Who needs to be there? What does each partner bring? What can community and system people learn from each other? How are differences valued? What are the values and assumptions about consumers/ communities, government systems, policy, the specific situation being addressed.

Create a Shared Environment

Dropping consumer and community representatives into a system environment without support makes equality and collaboration difficult. Many consumer and community representatives have had personal experiences where the health system has failed them. This may be both the motivating passion and the knowledge they bring to policy discussions. (See Knowledge Resource Base - Figure 2.) For example, women who have been sexually assaulted have used their anger to change the criminal justice system. Bureaucratic environments seldom demonstrate their interest in experiential knowledge and the expressions of passion that can create change.

Systems people bring professional knowledge in their field and understanding of how the system works. System participants are often skilled at reading and writing bureaucratic and professional documents, participating in discussions, chairing meetings, and focusing on tasks. They are paid as professionals.

Consumer and community participants may not bring the same skills, and are usually donating their time. These differences can present barriers that are never overcome. Accessibility is critical to consumer and community participation -

accessible buildings for people with physical limitations, accessible information through plain language writing or alternatives to print, skills training in meeting participation and facilitation and policy process, payment of transportation and child care costs and possibly honoraria. A facilitator, outside the interests of the parties, can help to address differences and develop approaches that lead to equality in participation.

How accessible is the location, information and process to consumer and community participants? Is there a balance between system and consumer or community representatives? Is a facilitator needed to establish a shared environment and process?

Make Sure the Product Reflects the Process

Policy documents and reports are often written by "experts" and do not necessarily reflect the language and experience of participants. Often participants find out about the results of their work through the media or not at all. Participation needs to be respected and valued by sharing the results of the work with those involved.

Consumer and community participants sometimes say - *"What was the point? Nothing I said is in there!"*

Is the policy understandable to the people it affects? Are the voices and experience of participants reflected? Did participants view a draft before it was finalized? Were participants given information about the results of their work?

Models to Consider

There is no easy solution to involving consumers and communities in government policy development. No clear path or step-by-step model for policy development emerged out of the experiences of the projects. However, the following two models are useful frameworks for planning policy development activities: the Organization Environment Model ensures that consumer/community participation is grounded in organizational values and goals; the Knowledge Resource Base values the contribution of consumers/communities through experiential and customary knowledge in a balanced approach to issues.

Organizational Environment Model

The organizational environment model shows that values are the centre of an organization. Mission and goals generate from values, followed by policies and practices. It is essential that policies be grounded in the values of an organization.

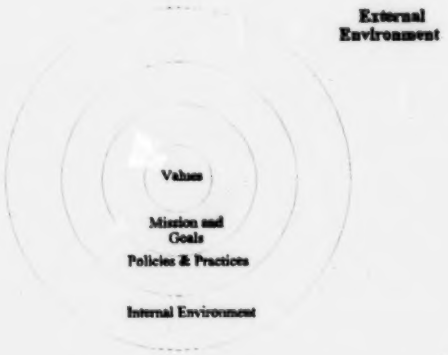

Figure 1 - Adapted from Barb Thomas, YWCA Toronto

Using this model can ensure that values about consumer and community participation are defined and explicit. And further, that policies and practices about participation exist. The model can be a useful tool in clarifying the process and the extent of involvement of others in policy development.

For example, in developing child care policies: Is consumer/community valued? Is this expressed in the mission and goals of the organization? Is a policy and program in place to ensure transportation and child care for community participants? Asking these questions will help to create organizations that truly value consumer/community participation.

Knowledge Resource Base

The Knowledge Resource Base (KRB) was developed by the Canadian Mental Health Association (CMHA) to describe the different kinds of knowledge that contribute to a full understanding of mental illness. It's purpose is to clarify the knowledge and expertise needed to understand a health problem.

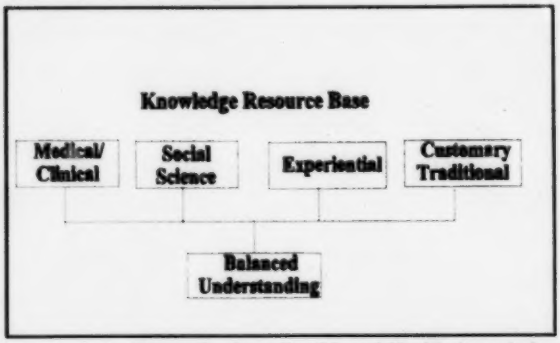

Figure 2 - Canadian Mental Health Association
A New Framework for Support for People with Serious Mental Health Problems 1993

This model can be applied to a wide-range of health and social issues and can be used when community groups or government agencies are gathering information relevant to a particular policy and deciding who to partner with.

The types of knowledge that build balanced understanding are:

Medical/Clinical - the diagnostic approach - territory of medicine, psychology, drug treatment, psychotherapy

Social Science - knowledge that defines the nature and influence of the social context, that takes into account external stressors such as poverty, unemployment, homelessness, abuse and social dynamics such as gender

Experiential - knowledge that comes from the inside, from living with the issue, experiencing its effects on one's own feelings and relationships, on life in the family and in the community.

Customary/Traditional - knowledge transmitted informally, handed down through generations by word of mouth, taken from our cultural environment -attitudes, beliefs, values, stereotypes. Both positive and negative, these vary from culture to culture. (e.g. Aboriginal people have traditional ways of dealing with health issues, as have third world societies, and all cultures have their own stigma issues.)

Using this model can ensure that all types of knowledge are considered in program and policy development. It reminds us that categories such as medical and scientific knowledge are given greater power, and that by bringing other kinds of knowledge to the table through consumer/ community participation, the balance is adjusted and power differences redressed.

For example, in the issue of caregiver stress: What medical/clinical information is relevant? What does social science literature tell us about the effectiveness of approaches? What do caregivers feel they need? How will community values or norms affect policies?

Conclusions

The experiences of four Atlantic region projects show the desire for citizens to get involved and the hope and enthusiasm expressed by that involvement.

Community/consumer led processes build trust. The various tools and processes the projects developed enhanced the capacity of communities to participate more confidently in health reform, and to partner with various sectors. Individuals who participated are more confident of the value of experiential knowledge and more aware of the importance of clarifying values.

Community groups also became more realistic about the limitations of community efforts to influence policy. Their work did not always have a direct policy impact. In theory, health systems recognized the need to work in partnership with the community in reforming health systems. In practice, they were not always ready to do this.

Since the health reform process starts with individual changes in thinking and behaviour, the spin-off effects from projects will never be fully known. There were, however, some positive impacts from these projects. For example, in PEI the Women Influencing Healthy Public Policy project identified a need for material which demystified the health reform process. In response the PEI Health Policy Council developed plain language materials which helped people to understand the goals of health reform.

All projects helped establish connections between community people and key people who work within the health system. The personal contacts developed during the projects mean that community and government people better understand each others contribution and are in more frequent contact.

If communities are to be more involved in policy development in the future, the policy development process needs to be clearly defined so that potential contributors can know the extent or limits of their influence. Systems will need to develop policies which insure there are resources and support for consumer participation, and practices that ensure the system is ready to partner with communities.

How to Contact Us

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Resources available:

- *Speaking for Ourselves* - videotape
- *Speaking for Ourselves - Community Participation Manual*

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Resources available:

- *Greater Saint John: A Healthy Community - Healthy Communities Project Report -Foundations for Action*
- *Greater Saint John: A Healthy Community - Discussion Guide*
- *Working Together for Healthier Communities* New Brunswick Healthy Communities Group

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Resources available:

- *Mental Health Consumers Participation in Self-Care, Recovery and Social Action* Training Manual

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Resources available:

- *Partnerships for Health - First Aid Kit* - a partnership workbook
- *Resources for Health* - Brochure of health resources

- or -

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